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Digital Cohorts within the Social "Mediome": An Approach to Circumvent Conventional Research Challenges?

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Barriers in Conventional Research

Medical knowledge, culminating from the collection and translation of patient data, is the primary objective of the clinical research paradigm. The successful conduct of this traditional model has become even more challenging with expansion of costs and a dwindling research infrastructure. Beyond systemic issues, conventional research methods are further burdened by minimal patient engagement, inadequate staffing, and geographic limitations to recruitment. Clinical research has also failed to keep pace with patient demands, and the limited scope of well-funded, disease-specific investigation has left many patients feeling disenfranchised. Social media venues may represent a viable option to surpass these current and evolving barriers when used as an adjunctive approach to traditional clinical investigation.

The term social media (SM) most commonly refers to relatively public Internet-based communication platforms that enable users to consume and disseminate information. The most popular SM venues currently include Facebook, Twitter, YouTube, and independent online forums (Table 1). These digital platforms support sharing multiple forms of media including text, images, and videos between users that interact within a wide realm of medical groups and genres (e.g. specific diseases, symptoms, etc.). This collective "mediome"[1] is a relatively untapped resource for clinical study, but research applications utilizing SM methodology have begun to produce real study benefits in an array of diseases. Effective implementation of this technology by interested investigators will require an in-

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depth working knowledge of digital venues beyond their own online social presence. A firm grasp of these applications can enable the contact of previously out-of-reach study participants, promote patient engagement and disease investment, and cultivate a community of interacting patients and researchers. This data-rich resource has already facilitated various aspects of biomedical studies, including dissemination of epidemiologic surveys[2], direct recruitment into clinical trials[3], collection of biologic samples[4], and extraction of patient-provided data all within SM platforms[5].

Advantages and Pitfalls in SM Research

SM is a new frontier containing a wide spectrum of clinical and qualitative data from connected users (patients). Collection and examination of either individuals' or groups' SM information use can provide insight into qualitative life experiences, just as analysis of biologic samples can enable dissection of genetic disease underpinnings. This mediome is analogous to the human genome, both in content and utility.[1] Analyzing data streams from SM for interpersonal interactions, message content, and even frequency can provide digital investigators with volumes of information that otherwise would remain unattainable.

There are many advantages to scientific interrogation of the social mediome, specifically as applications within SM have no physical bounds, encourage information exchange among stakeholders, and work in real time. Patient access to clinical studies and individual investment can limit both conventional and unconventional approaches to research. However, SM far exceeds the geographic limitations determined by location of patients and academic systems, thus expanding the available recruitment population dramatically (Table 1). Patient-to-patient communication is facilitated by the format of most SM venues (Facebook and other Internet forums), thus creating an enriched collection of disease testimonies, symptom discussions, and treatment effects. In fact, patients frequently use SM to form online support groups in order to share experiences with similarly afflicted patients and families. These groups and their documented communications are valuable, as qualitative patient data can provide a high resolution of variable patient metrics to investigators.[5] Lastly, data collection from SM can occur continuously in real time and with little cost. Facebook, Twitter, and YouTube are free to use, and while online Internet forums may incur small monetary investments (typically $15 to $50 per month). Because of study heterogeneity, it remains challenging to compare costs between a SM-based research study and a similar traditional clinic-based approach. Yet, historically, costs incurred to SM research pioneers have been dramatically lower than cost estimates of conventional approaches in the clinic.[6]

Several limitations and potential risks of SM for medical research should be addressed, including the possible compromise of privacy and confidentiality, the use and dissemination of medical advice and information, potential demographic biases, and a required trust of the investigator by patients. Many of these challenges can be similar to traditional methods, yet as in the conventional model, careful management can drastically reduce unwanted study issues.

The risk of HIPAA violations must be seriously considered in the context of patient-researcher interactions on SM. Because of the relatively public nature of these venues, patient confidentiality may be at risk if patients choose to divulge personal medical information. However, if proper protective measures are taken to ensure that the venue is secure (e.g., a private or closed group on Facebook or a by-invitation-only online Internet forum), and the researcher vets all patients who request entrance into the group, this risk may be minimized. Moreover, in order to further reduce any legal liability, the researcher should not provide any medical advice to patients who participate in a SM study. The drive to provide medical direction in study patients with need may be strong, as collaborative relationships between investigator and patients are likely to form. Furthermore, digital access to investigators on SM commonly becomes easy for patients. Safe approaches to communication could include redirecting patients to consult with their own doctor for advice, unbiased dissemination of disease-specific educational materials, or depiction of only institutional review board-approved study materials.[7,8]

An investigator-driven interactive community (e.g., Facebook group) may bolster patient involvement in SM studies and help facilitate disease-specific research. However, because most SM venues facilitate patient-patient interactions, misleading or incorrect medical information may be spread quickly between patients and could be misconstrued as official medical advice.[9] In order to mitigate this, a researcher or trusted study personnel must actively moderate the digital venue in order to prevent the spread of counterproductive information.[7] Although it is not possible to completely eliminate the sharing of unverified information, regular moderation will reduce the potentially negative impact of such sharing.

The perception that only younger populations use SM may appear to be a significant limitation for its implementation in clinical research. However, this limitation is rapidly becoming less significant, as recent studies have shown that the use of SM has become increasingly common among older adults. As of 2014, over half of the US adult population uses Facebook, including 73% and 63% of Internet-using adults age 30–49 and 50–64, respectively.[10] SM may not be suitable for all diseases, yet there is likely significant demographic overlap for many disease populations.

Finally, it is imperative for researchers to gain the trust of patients on SM in order to effectively utilize these venues for research purposes. Because patient-researcher interaction does not occur face-to-face on these platforms, gaining the trust of patients may be more difficult than it would be in a clinical setting. Thus, patient-patient and patient-researcher communications within SM platforms must be carefully cultivated in order to instill participant confidence in the research being done on their behalf. Author CL has established a SM educational model for this exchange.[4] Specifically, he provides patients with a distillation of current field research by posting updates in a research-specific Facebook group and on Twitter. This model not only empowers patients with disease education; it also solidifies the importance of patient investment in disease-specific research. Furthermore, invested patients bring ideas to research, take a more educated and proactive role in their care team, and ultimately return to seek more study involvement.

A number of studies have shown SM methods to be an effective means of collecting data and improving quality of care for patients. One randomized controlled trial found that the use of SM to disseminate instructional information to patients alongside the traditional educational pamphlet increased patients' quality of bowel preparation for colonoscopies.[11] Another study successfully utilized the Crohn's and Colitis Foundation of America Partners Internet Cohort of more than 14,000 patients to examine factors associated with fiber consumption in inflammatory bowel disease and whether fiber was associated with disease flares.[2] Additionally, several studies have assessed the roles of mobile apps, remote health sensors, and telemedicine in research and patient care and have found that these tools are effective at providing more complete care in real time and with decreased costs.[12] Riaz and Atreja[13] note that the most significant barrier to the use of these techniques in research and patient care is provider acceptability, in addition to the need for strict HIPAA compliance to ensure patient confidentiality. Keeping these limitations in mind, the aforementioned studies lend significant support to the effective use of SM as adjuncts to traditional clinical investigation.

SM in Rare Disease Research

Rare diseases (conditions with a prevalence of less than 200,000 patients in North America), in particular, are prime for high yield results and community impact using novel SM approaches. This is the result of established digital support groups, publications with historically low study numbers, and few focused investigators. Several studies of rare diseases have demonstrated considerable advantages of using SM as a study tool. For instance, an existing neuroendocrine cervical cancer Facebook support group was recently used to recruit a geographically widespread cohort of patients with this rare cancer. Through an online survey posted in the Facebook group, patients were able to provide specific information on their treatment, disease and symptom history, current disease status, and quality of life, including various psychological factors. Without the use of SM, collecting this information would have been virtually impossible, as the patients were treated at 51 cancer centers across the country.[14]

Similarly, a 2014 study investigating Fontan-associated protein-losing enteropathy and plastic bronchitis aimed to compare patient participation in surveys posted on SM with participation in more traditional research modalities. The authors found that 84% of responses were referred from SM. As of 2014, this cohort was the largest known group of post-Fontan protein-losing enteropathy and plastic bronchitis patients in existence.[15]

Currently, the use of SM in hepatology research, specifically focused on autoimmune hepatitis (AIH), is under exploration at Indiana University. AIH is a rare autoimmune liver disease that results in immune-mediated destruction of liver cells, possibly resulting in fibrosis, cirrhosis, or liver failure if treatment is unsuccessful. Author CL has used both Facebook and Twitter to construct a large AIH study group of individuals affected with AIH called the Autoimmune Hepatitis Research Network (AHRN; 1500 members) during the past 2 years.[4] Interested individuals have joined this research group after searching for AIH online support groups or reading shared AHRN posts on other media platforms. Between April 2015 and April 2016, there were posts by over 750 unique active members (>50% of

the group contributes to discussions), most of whom appear to be either caregivers of AIH patients or AIH patients themselves.

Preliminary informational analysis on this group has shown that CL and colleagues have been able to uncover rich clinical and non-clinical information that would otherwise remain unknown. This research was performed by semi-automated download of the Facebook group's content and subsequent semantic analysis. Qualitative analysis was also performed by direct reading of patient narratives. Collected clinical information has included histories of medication side effects, familial autoimmune diseases, and comorbid conditions. The most common factors patients were unlikely to discuss with a provider (e.g., financial issues, employment, personal relationships, use of supplements, alcohol usage) were frequently discussed in the AHRN group, allowing a more transparent view of the complete disease experience.

Beyond research conducted in the current paradigm, the AHRN has provided a rich community construct where patients offer each other social support. The patient impression of AHRN on Facebook has been overwhelmingly positive, as patients often wonder why such a model has not been employed with other diseases. The close digital interaction CL has had with numerous patients and families has promoted other benefits of this methodology, as over 40 new AIH patients from outside Indiana have traveled to Indiana University for medical consultation despite no advertisement.

Conclusions

SM has the potential to transform healthcare research as a supplement to traditional research methods. Compared to a conventional research model, this methodology has proven to be cost- and time-effective, wide reaching, and similarly capable of data collection. Utilization of SM in research has tremendous potential to direct patient-centered research, as invested patient collaborators can take an active role in their own disease and may hone investigatory focus on stakeholder priorities. Limitations to this method are known, yet if implemented cautiously, these can be mitigated. Investment in and application of the social "mediome" by investigators and patients has the potential to support and transform research that would otherwise be impossible.

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Abbreviations

SM	social media
AIH	autoimmune hepatitis

AHRN Autoimmune Hepatitis Research Network

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Table 1

Statistics, Usage, Advantages, and Pitfalls of Social Media in Research

	Facebook®	**Twitter®**	**YouTube®**	**Internet Forums**
Official website	www.facebook.com	www.twitter.com	www.youtube.com	N/A
Available since	2004 (College students) 2006 (General public)	2006	2005	Early 1990s
Operated By	Facebook, Inc.	Twitter, Inc.	Google, Inc.	Independent web server owners
Popularity (Reach)	Best (1 billion +)	Good (100 million +)	Very Good (800 million +)	No reliable estimate; not as popular but more targeted
Types of media supported	Typed text; images; embedded videos	“Tweets” (messages of up to 140 characters); linked images; linked videos	Videos; some typed text in video comment sections	Typed text; linked images; linked videos
Customizability	Very little	Very little	Very little	Usually high
Financial cost	Virtually zero	Virtually zero	Virtually zero	Cost of a web server (typically $15–50 per month)
Data extraction difficulty	Qualitative: Easy Big data: Difficult	Qualitative: Easy Big data: Difficult	Qualitative: Easy Big data: Difficult	Qualitative and big data extraction are easy if the forum is database-driven
User privacy	Groups feature: Reasonable Remainder of site: Marginal (Users typically use real names)	Marginal/Reasonable (users typically use real names but may be masked by screen names)	Reasonable (users masked by screen names)	Best (can be kept completely private except to invited users only; users masked by screen names)
Communication direction	Usually highly multilateral	Somewhat multilateral; no formal post-reply structure	Relatively unilateral; users may post comments on videos	Usually highly Multilateral
Advantages for clinical research	Broad cohort of users; can form private groups	Quick, text-based communication	Multimedia (audio/video) communication and feedback of health information	Privacy is easy to ensure; complete control of the venue; data extraction is simpler
Potential pitfalls for clinical research	Most users utilize real names on the site (Privacy risk)	Health discussions hampered by short (140 character) limit	Few chances for patient interaction (limited to comments)	Requires minor but non-trivial technological support to set up; has financial costs